
Guest editorial

End-of-life decisions and the law

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The recent decision in the Court of Session in Edinburgh in the case of Janet Johnstone brings the issue of end-of-life decisions back into the forefront of public debate. Many groups in the community and many individuals have a special interest in what we should do in respect of those whose conscious life is at an end although their physical existence is not.

As most will know, the Scottish courts were, for the first time, being asked to reach a decision about whether or not it would be lawful to withdraw nasogastric feeding from a woman in persistent vegetative state (PVS). The nature of the diagnosis means that Mrs Johnstone, as in the earlier English case of the Hillsborough victim, Tony Bland, has a functioning brain stem – which maintains basic functions such as breathing and circulation – but her higher brain is so damaged that she can feel and experience nothing. Although people in this condition can appear to have sleep/waking cycles and may respond to certain fundamental stimulæ, they are irretrievably comatose.

Essentially, the courts, when considering such cases, are being asked to judge what is the “right” thing to do. The person is not dead for legal or medical purposes, yet there seems to be no purpose – beyond extending insensate existence – to be served by continuing to provide nutrition and hydration. Of course, for some people, the mere fact that the person is not dead means that everything should be done to maintain existence. For others, the issue is one of compassion – the patient will exist perhaps for decades with no life of any quality at all.

The problem for the law is how it should react. We live in a community which, for obvious and clear reasons, espouses the sanctity of life. It is for such reasons, and on the basis of this principle, that we do not endorse killing any other human being. Yet, the advances in medicine have left a grey area which makes it less easy to be quite so clear cut. People may be kept alive in situations which for many would be unacceptable because we know how to keep them alive, and because those caring for them are uncertain about their legal liability should they fail to keep that existence going. The conditions which used to intervene and result in the death of that person can now, by and large, be cured. The question now is not

so much **how** we can extend existence but rather **whether** we should, and this is arguably the most difficult of all choices.

As in the case of Tony Bland, the outcome in Mrs Johnstone’s case was that the court authorised the removal of the assisted feeding/hydration. Since no appeal was made from this judgment, Mrs Johnstone’s family and doctors agreed to withdraw the nasogastric feeding and Mrs Johnstone died some two weeks later. There is no doubt about the beneficent intentions of those who sought leave to allow her to die, but there is a massive paradox in the law.

When asked to adjudicate, the courts in the UK have built tests on which they can reach conclusions about whether or not the life of a person can be ended – most commonly in cases concerning patients in persistent vegetative state and handicapped neonates. By utilising effectively a “best interests” test, they have found it possible to endorse the clinical recommendation that life should not be prolonged. Yet, these are the two groups who might be said to be most acutely vulnerable, and in the light of that, those most in need of a stringent legal test. Put another way, if a competent, adult human being requests assistance in ending a life which **for them** is intolerable (that is, it is no longer in their own “best interests” to survive) any doctor who assisted in that request would be guilty of a criminal offence. Yet where wishes are not known or could never have been expressed, the courts take upon themselves the task of reaching a conclusion, and render the doctor non-liable.

This is particularly interesting in Mrs Johnstone’s case. Unlike the Bland case, where the House of Lords was hearing the case as a civil one, the Court of Session heard the case with Scotland’s Chief Criminal Law Officer – the Lord Advocate – involved. Scotland’s senior Civil Judge (The Lord President) set out the framework within which decisions could be taken (“best interests”, or that treatment would provide no benefit for the patient) whilst expressing the view that not every case would have to go before a court (unlike the English position). In a move which takes Scots law ahead of its English counterpart, the Lord Advocate subsequently issued a policy statement to the effect that

– whilst he also did not feel that every case would necessarily have to be heard by a court – he would offer immunity from prosecution to every doctor who disconnected the nasogastric feeding from any patient in PVS where the Court of Session had authorised this.

The net result is that doctors and families may choose to continue to make decisions on the basis of the Lord President's guidelines, but only those who have court authority will be guaranteed immunity from prosecution. The prudent doctor will doubtless seek court approval before acting to remove the feeding. However, this still does not address the fundamental issues. Although, in my view, the doctor in Scotland is in a much safer legal position than his/her counterpart elsewhere in the UK because a direct and unequivocal statement concerning criminal liability has been made, there remain a number of residual doubts about the basis on which the law will judge such cases.

These are too many and varied to consider in such a short article, but two are especially deserving of attention. The thrust of UK decisions in cases of this sort has been that the decision is based on "best interests". Although the Scottish courts defined this as being treatment which is no longer of benefit to the given patient, it remains a vague test and one which is relatively unhelpful once a diagnosis of PVS has been made. The very crux of the diagnosis is that the patient has no interests at all, far less best ones, so how is one to decide that the test has been met? The point is that – in our fear of addressing the possibility that there may be conditions which make death preferable to life – for example, where a competent person has decided that this is so and in an effort to avoid confronting the whole euthanasia debate, we have developed tests which are philosophically and ethically flawed in order that the "right" decision can be made.

All individuals and professionals who deal with friends, relatives, clients and patients are aware that sometimes maintaining existence is not the humane option, yet our law will penalise anyone who helps the person who asks for relief. At the same time, it will apparently not penalise those (so long as they are clinicians) who stop providing sustenance when nobody can know what would have been chosen by the individual and on the basis of a test which is inherently flawed.

Moreover, doctors cannot escape the consequences of their actions on the basis of the acts/omissions doctrine. Whether it is an act or an omission to suspend nutrition and hydration is legally irrelevant in such cases, because there is a pre-existing duty of care which renders them as liable for their omissions as for their acts. In addition, the intention is precisely the same as is the motive. In other words, whether we like it or not, the time has surely come for the

whole issue of end-of-life decisions to be reopened.

Analysis of legal decisions from selective non-treatment of handicapped infants, to patients in PVS, to double effect, to competent refusal of life-sustaining treatment to active euthanasia shows one major thing – that our law is inconsistent, sometimes incoherent. Yet, one of the things that we can legitimately expect of our law is formal justice – that fairness will prevail. For the moment, only those who have no say can apparently be helped by the legal process towards the termination of an existence which we would not wish for ourselves. But if we choose for ourselves, we cannot be assisted. This is surely the ultimate paradox and one which requires resolution.

Arguably, the Scottish courts have made some progress. The complexities and variations in the Bland judgment are lacking in the final judgment of Lord Cameron. No attempt was made to argue about the difference between acts and omissions and the problem as to the existence or not of the *parens patriae* jurisdiction was resolved. But there remain serious questions about the tests which are used and the extent to which they conflict with other principles which we value – such as autonomy, respect for persons and individual dignity. Let no one be in any doubt. Mrs Johnstone's death was not dignified – dehydration is certainly not that. But if we do feel that her existence should not be extended, what might have been dignified would have been a single act which ended it. This our law will not allow.

What we have seen yet again is an avoidance of the main question by reacting to a particular set of circumstances and attempting to accommodate them. Of course, the court was not asked to consider the means by which Mrs Johnstone might die, only whether or not this should be permitted, and the judiciary can only answer those questions which are put before it. Based on this truth, it seems inevitable that *ad hocery*, however well intentioned, will continue to dog this most sensitive of issues. Moreover, in striving to reach appropriate conclusions, our judges will be thrown back on tests which are at best arguable and at worst inappropriate.

What the Bland and Johnstone cases surely argue for is: 1) a legislative framework which concedes that there is no absolute commitment to the sanctity of all life, and 2) guidelines – based on principle – which can point the decision-makers to a consistent, accountable and transparent decision. Or, of course, legislation might outlaw all such decisions. Whatever the outcome, there is a value in certainty, both for those caring for these patients and for those of us who may one day end up in such situations.

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